

# The Study of Memory and Aging in Native Americans



Nina Silverberg  
December 17, 2012

# Two part talk

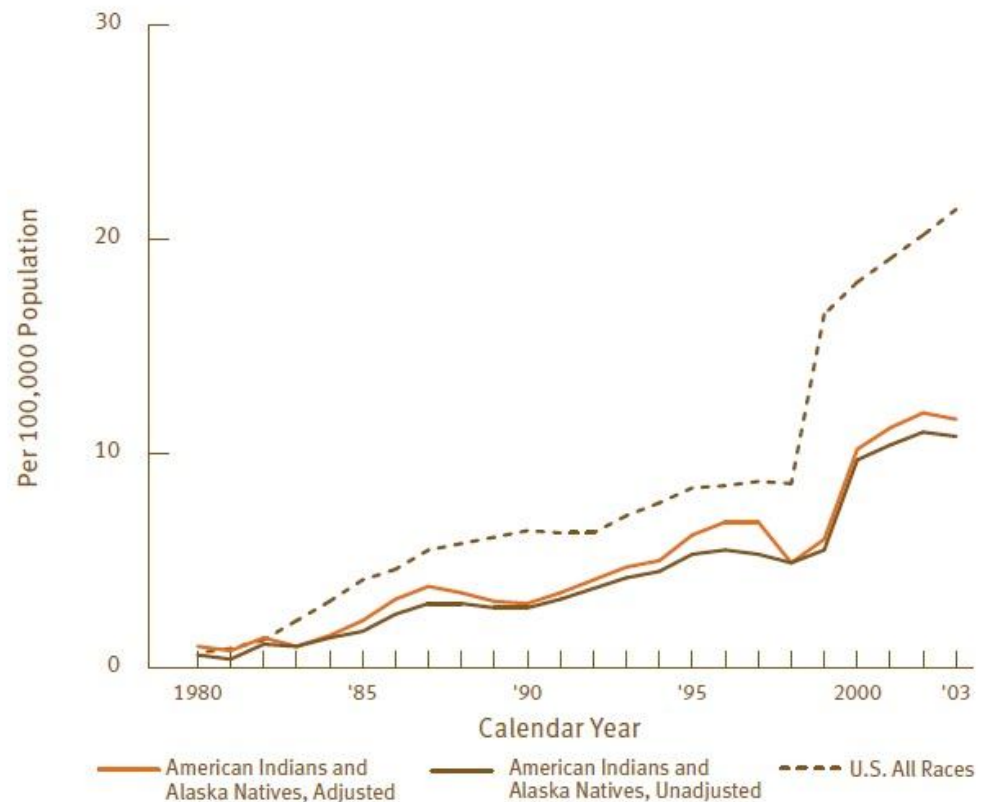


- ❧ Part 1: Updated version of a talk I frequently gave about 10 years ago
- ❧ Part 2: What we are doing about it!

# Mortality statistics from “Trends in Indian Health 2003”

The AI/AN age-adjusted Alzheimer's disease rate (1.0) for years 1979-1981 increased to 11.6 for 2002-2004. The U.S. all-races rate (21.4) for 2003 is 1.8 times the 2002-2004 rate (11.6). These AI/AN rates have been adjusted to compensate for misreporting of AI/AN race on the state death certificates.

Chart 4.52 Age-Adjusted Alzheimer's Disease Death Rates



# Two things to notice



- ❧ AD is increasing dramatically in both groups
- ❧ American Indians have a MUCH lower prevalence
  - ❧ Maybe there is a genetic or environmental reason? (i.e., maybe it's true)
  - ❧ Maybe AD is underdiagnosed and/or underreported in this population (i.e., maybe it's false)



# Indian Country: Native Approach to Dementia Emphasizes Human Spirit

Carol Berry

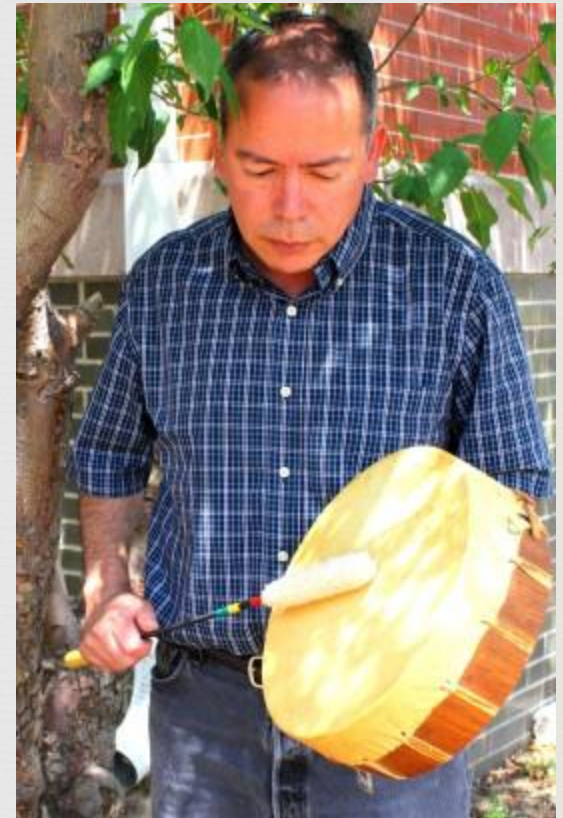
July 23, 2012



For David Maes, of Hopi/ Apache descent, a presentation he attended on aboriginal and Australian approaches to Alzheimer's disease resonated immediately and he "knew that everything was coming together" in a new way of viewing the brain disorder.

Maes is establishing the nonprofit Taawa Energy Center (Taawa) in Denver to care for elders living with dementia through an approach that seeks and uses "the essence of the person" for healing. He points out that "Taawa" is the Hopi word for "sun."

The need is apparent. Government experts put the number of people in the U.S. with Alzheimer's at 5 million, and it's noted that Alzheimer's appears to occur at about the same rate among older Native Americans/ Alaska Natives.

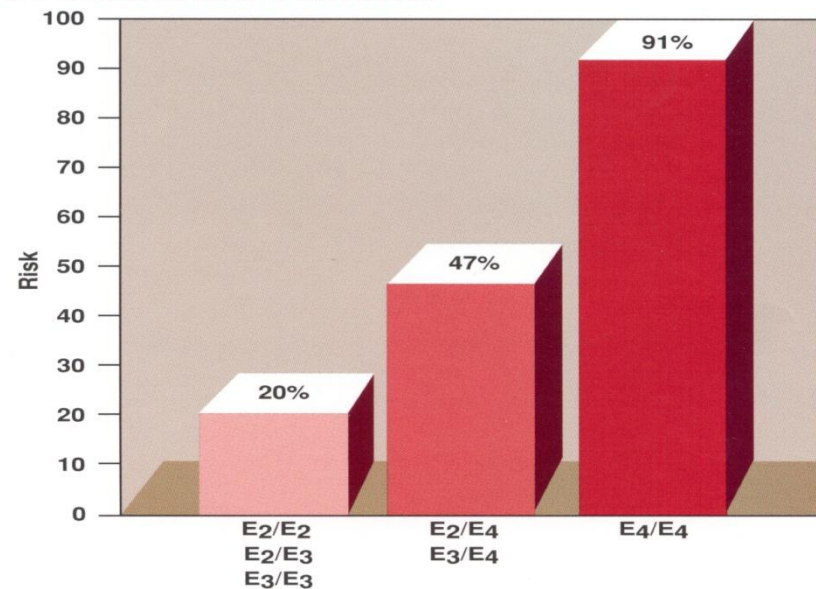


# Apolipoprotein $\epsilon 4$



- ❧ Genetic risk factor for AD
- ❧ Studies suggest that Apo  $\epsilon 4$  may be less frequent AND less associated with dementia in some Indian populations

*E<sub>4</sub> Allele as a Risk for AD by Age 80 in Dementia Patients*



Adapted from: Corder, et al., Gene Dose of Apolipoprotein E Type 4 Allele and the Risk of Alzheimer's Disease in Late Onset Families. *Science*, 1993, 261:921-923.

# Reasons for lack of research - few elders



- ❧ Native Americans have had a briefer life span, so people may not have lived long enough to become demented.
- ❧ However, life expectancy is generally increasing:
  - ❧ 51 years in 1940
  - ❧ 73.2 years in 1994
  - ❧ 72.6 in 2004
- ❧ Still lower than Caucasians (77.8, 2004 data)



# Reasons for lack of research - trust



- ❧ Tribes have had bad experiences with previous researchers
- ❧ Some examples:
  - ❧ Researchers do not provide data to community after study is completed – no benefit to participants
  - ❧ Researchers are unaware of or outright disrespectful of cultural practices
  - ❧ Researchers are outsiders, may not be trusted by community – may skew results!
  - ❧ Recent case with Havasupai and ASU



# Reasons for lack of research - culture



✧ Maes himself views those with Alzheimer's in a unique way: He believes that "among aboriginal and Native people, those with dementia [of which Alzheimer's is one form] are the spiritual people, beginning to leave this world to enter a world where everything is positive and good. There's no judgment in that world."

# Why we need to do the research

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- ❧ The population of Native Americans over 65 years old will increase by 391% between 2010 and 2050.

Calculated from Census document “THE NEXT FOUR DECADES The Older Population in the United States: 2010 to 2050 “: <http://www.census.gov/prod/2010pubs/p25-1138.pdf>

- ❧ Native Americans have much higher rates of many risk factors for dementia
- ❧ Because there has been so little research, we do not have appropriate assessment tools for Native American people, although this is improving.

# Why we need to do the research



- ❧ Identify cases of dementia, determine prevalence
- ❧ Can help tribes with health care planning
- ❧ People with dementia need special kinds of help
- ❧ Caregivers need lots of information – help understand and prepare for changes in elders



# Challenges



## ∞ Diversity

- ∞ 562 federally recognized tribes.
- ∞ At least 200 different languages.
- ∞ Differences between reservation, rural and urban dwelling members.
- ∞ Differences in involvement in both traditional culture and in dominant American culture.

∞ *Important **not** to generalize*

# Challenges



- ❧ Lack of awareness of dementia and its associated medical and non-medical treatments as well as appropriate health care
- ❧ Few Native Americans involved in conducting this type of research - so researchers are outsiders, not familiar with culture
- ❧ Currently, don't have appropriate assessment tools

# Conclusions



- ❧ Much more research is necessary
- ❧ Must involve members of the community in doing the research
- ❧ Education and outreach are important first steps



# Final Thoughts



❧ When an Elder speaks, be silent and listen.

❧ Mohawk

❧ Cherish youth, but trust old age.

❧ Pueblo

❧ Never see an old person going to carry water without getting a bucket and going in their stead.

❧ Unknown

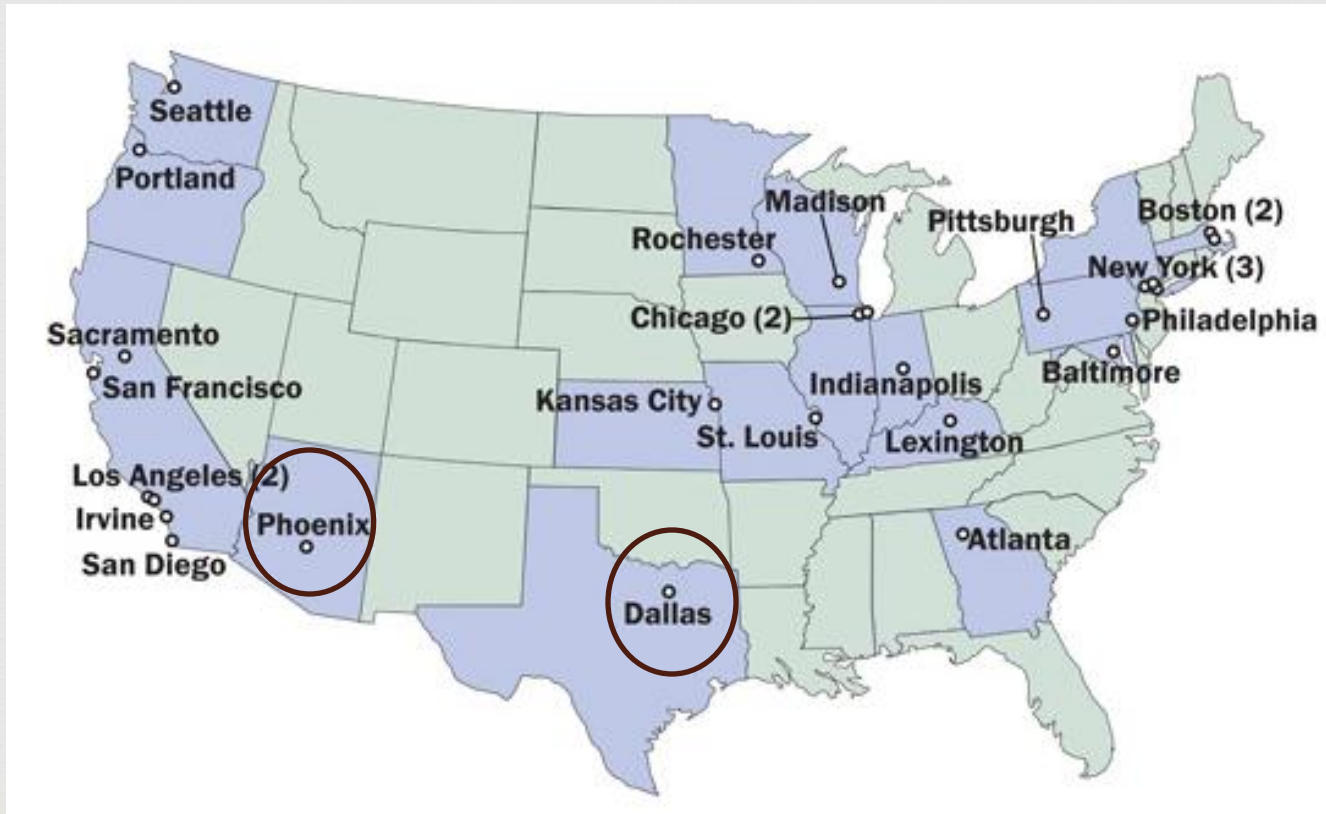
❧ We will be known forever by the tracks we leave.

❧ Dakota

# Part 2



Two NIA funded Alzheimer's Disease Centers focus on Native American Outreach





Banner Alzheimer's Institute



# **Raising Awareness Of Alzheimer's Disease in Arizona Native American Tribes**

Banner Alzheimer's Institute  
Phoenix, Arizona





Banner Alzheimer's Institute

# Historical Development/Leadership of the Native American Program

- The Native American Program began in 2003 at Sun Health Research Institute, Sun City, Arizona
  - Dr. Marwan Sabbagh (neurologist); Dr. Nina Silverberg (psychologist) and Minnie Jim (Outreach Coordinator)
  - Goals:
    - Increase knowledge and awareness of Alzheimer's and Dementia among the Arizona urban Native American communities and Arizona Indian Tribes
    - Identify and recruit elderly urban Native American volunteers for screening of normal aging and cognitive evaluations (ADCC)
  - Outcome:
    - To improve healthcare for the native American population
- The Native American Program transitioned leadership in 2008 to Banner Alzheimer's Institute, Phoenix, Arizona



Banner Alzheimer's Institute

# Outreach and Awareness: Advisory Groups/Awareness Materials

- Established a Native American professional focus group in 2009 to serve as an advisory capacity
  - Provide input for current/future outreach & education activities
  - Advise on annual conference
  - Members represented from:
    - Arizona Department of Health Services, Arizona Long Term Care System (Medicaid), Select Tribes, Intertribal Council of Arizona Elderly Program (Area Agency on Aging for 20 of the Arizona Tribes), Urban Indian Programs
- Outcome resulted in:
  - Targeted education, outreach and annual conference activities
  - Education booklet specific to Native American population and Alzheimer's Disease/Dementia
    - "Navigating through Memory Loss"
  - 8-minute DVD on "Caregiving and Dementia in Native Americans"



# Outreach and Awareness: Annual Statewide Conference

- Sun Health Research Institute began an annual conference in 2004
  - Initial three conferences focused on more traditional medical topics and healthcare providers
  - Two conferences held in urban area; one in rural area
  - ~100 – 150 health care professionals attended
- Since 2007, an advisory planning committee has expanded the agenda to include issues of living with the disease, caregiving, prevention, wellness, etc.
  - Up to half of all conference speakers are American Indians
  - Up to 300 participants attend annually; 60% family caregivers/40% professional caregivers
  - All of the Arizona tribes have attended with representation from another 10 tribes from other states
  - In 2009, added pre-conference ½ day intensive for case managers/ community health representatives
  - Conference moves to various locations around the state each year and is provided at a tribal owned hotel/casino
  - Funding for the conference is provided by the John and Sophie Ottens Foundation since 2009
    - Free for all conference attendees



Banner Alzheimer's Institute

# Outreach And Awareness: Specific Community Needs

- Numerous community education programs provided to both urban and reservation dwelling community participants and family caregivers
- Routine presentations provided at other statewide American Indian conference by BAI staff
- Targeted medical education provided regarding diagnosis/treatment of Alzheimer's disease/dementia to both IHS/638 tribal communities and health centers
- Annually, BAI is reaching >1,000 family caregivers/community members and > 500 professional caregiving staff
- Received \$200K award from Tohono O'odham and Gila River tribes to develop "culturally sensitive/appropriate memory screening and brain health programs" in 2013





# Native American Cohort Group

- Purpose is to study cognitive aging in normal Native American elders
  - Original study included ~ 60 elders
  - 18 are still participating; other lost to f/u or declined to continue
- Testing includes:
  - Physical and neurological examination
  - Review of medical history
  - Neuropsychiatric testing
- Process:
  - Participants are contacted by phone, or at the Senior Center
  - Date is schedule
  - Transportation is provided
  - Elders are met by Outreach Coordinator at BAI
  - Participants are given a Wal-Mart gift card for their time and effort
- Challenges:
  - Staying connected with participants
  - Giving feedback to them to stay involved with the program
  - Making sure appointments are coordinated/confirmed/in the best location
- Continue to follow up and visit the elders at the Native American Senior Center or with home visits



Banner Alzheimer's Institute

# Summary

- The BAI Native American Outreach Program continues to be a very productive partnership between a health care organization and both tribal and urban Indian programs raising awareness about Alzheimer's disease and related dementias





# Choctaw Nation Memory Clinic

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# Recruiting For Native American Dementia Patients



- Cherokees In Oklahoma 1993 -1997
- Found that the greater the Cherokee heritage, the less likely to have AD  
(Rosenberg, et. al 1996)
- 1998 began relationship with the Dallas Urban Intertribal Center
- Formed Elders advisory board

 **Honoring Our Elders Memory Clinic**



# Cultural Understanding in Recruiting for Study patients in the Choctaw Nation



- **Dementia or Alzheimer's is not a familiar concept as there is no word for "dementia" in the Choctaw language**
- **Communication with those who have passed over to the "other-side"**

# Lessons Learned - Patience and Persistence



- ❧ **Hi, we're back!** Visit and revisit
- ❧ Choctaw Education Outreach Coordinator traveled 22,725 miles in Oklahoma in 2003
- ❧ New in 2004 – Memory Checks-Ups
  - ❧ Successful in screening of 166 elders
  - ❧ 23 were referred to Clinic study

# Choctaw Nation Memory Clinic

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# Honoring our Elders

